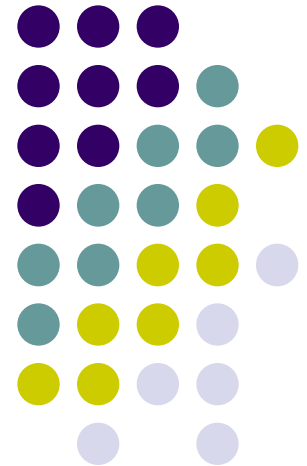


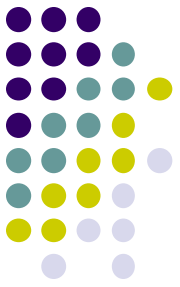
# Co-producing knowledge about LGBT cancer inequalities



Dr Julie Fish  
Reader in Social Work & Health  
Inequalities,  
Qualitative Methods In Psychology  
11 April 2014



# Health inequalities research in LGBT communities



- LGBT people often described as 'hard to reach' / seldom heard in research;
- Paucity of data on sexual orientation in NHS and cancer surveillance systems;
- Medical model of health – no differences.
- Changing attitudes;
- Increasing openness;
- National Cancer Equalities Initiative;
- Developing a research agenda
- More interested in taking part in health research.



# Coming Out About Breast Cancer

Research on lesbian and bisexual women's experiences of breast cancer

## Lesbian and bisexual women and breast cancer

ESRC knowledge exchange programme RES-192-22-0111



# Epistemologies of LB women's lived experiences of breast cancer



- What does it mean to have breast cancer when your partner is a woman? How do LB women feel about the prospect of losing their breast? Are partners more or less empathic? Do they display more or less supportive behaviours?
- Subtle and nuanced understandings of the complex interplay of their identities, experiences and values in their everyday lives and in their interactions with providers of services;
- Decisions not to undergo breast reconstruction: they encountered attitudes based on heteronormative constructions of femininity from surgeons providing care;
- NICE guidelines which recommended reconstruction immediately following surgery to remove the breast .

# Theoretical Frameworks : New Terminologies of Cancer



- Teratologies – tales of monsters and marvels that pervade the popular imaginary of cancer subcultures (Stacey, 1997)
- Breast cancer as a feminised and sexualised illness – the newsworthy body (
- Potts, 200)
- Survivorship - or living ‘with and beyond’ cancer (Doyle, 2008)

# Psychosocial Consequences: Managing a Changing Identity



- “Confrontation with a potentially fatal disease can focus the mind; it provides the opportunity for values to be reassessed, priorities to be examined and commitments and relationships to be re-evaluated”  
(Armstrong-Coster, 2004, p 1)
- This questioning becomes part of a new ‘cancer’ identity, whereby the individual tries to make sense, not just of his or her illness, but of life (Mathieson and Stam, 1995, p284)



NHS  
National Cancer Action Team



# Coming Out About **Breast Cancer**

Lesbian and bisexual women's  
experiences of breast cancer

Join us over a glass of wine and light refreshments for an evening to raise awareness about breast cancer in lesbians and bisexual women. This FREE event will be of interest to all women and organisations providing services to lesbian and bisexual women.

**Professor Sir Mike Richards**, National Cancer Director for England, will introduce the event and there will be a keynote speech from novelist, actor and comedian **Stella Duffy**.

Date: **6pm Wednesday 19 May 2010 • FREE**

Venue: **St. Anne's Church, Soho, London W1D 6AF**

RSVP by Friday 7 May to [mnelson@dmu.ac.uk](mailto:mnelson@dmu.ac.uk) or by phoning

**0116 257 7732**. Places are limited so please book early.

## Public engagement event

St Anne's Church,  
Soho – Mike  
Richards, the  
National Cancer  
Director presented a  
keynote speech.  
Service user and  
carer involvement





# Two linked projects

- Coming out about breast cancer in lesbian and bisexual women funded by National Cancer Action Team 2010
- Developing professional knowledge about breast cancer in LB women funded by ESRC Knowledge Exchange programme 2012





# Steering group (2009-2012)

- 3 LB women with breast cancer
- Head of Policy and Research, Breast Cancer Care.
- User inclusion manager, Macmillan.
- Public relations officer, Cancer Research UK
- Clinical projects manager, Metro centre, London.
- Development worker, Kairos (centre for health/well being).
- Academic, UCL.
- Nurse specialist, London regional cancer network
- NHS South West, Equality and Diversity Lead

# User involvement in health inequalities research



User involvement makes for research that is:

- better informed by the concerns and needs of the public and patients;
- based on methods that are more sensitive and enable the effective engagement of research participants;
- likely to elicit fuller and more open responses from participants because people with similar experience have been involved in formulating them (Beresford, 2007).

# PPI approaches in health research



- Designing study
- Recruitment of research participants
- Analysis of findings and write up of research report
- Research dissemination.
- Using the findings to make changes to service delivery

# ***Interactions with doctors and nurses***



“One of my visits to the oncologists...she was so business-like, no um, I didn’t feel that she was taking the time to see me as a human being”  
(Mercedes, cancer services user)

“I think it’s really weird that cancer has made a lesbian relationship acceptable, that’s what it really felt like to me. In lots of places, we maybe came across people who wouldn’t have given us the time of day but they did because I’d got cancer. I suppose partly because it’s their job to but I guess in some ways, we have probably changed some attitudes along the way as well” (Ursula, cancer services user).

# Involving partners in care



“My partner had breast cancer and although the care she received generally was good, our relationship was never acknowledged and at best I was treated as her 'friend' which at times we found difficult and stressful. I think if I had been a male partner, the health professionals would have included me more in discussions rather than turning their back to me and seeing me as 'irrelevant' when I went with her to the hospital”.



Cynthia Dixon - actor

# ***Heterosexism in cancer services***



“If we’d had someone treating us that was maybe, was very relaxed about, you know, our sexuality, or whatever, I think it might have just made it a bit easier to ask questions...you sort of worry about it sometimes and think, oh God, they are really uncomfortable with it” (Naomi, carer).

# ***Attitudes to breast reconstruction***



“The surgeon asked me at least twice, by saying like, it wouldn’t take much as I had quite a lot of excess fat there, that he could use that, and I said no, I really didn’t want a reconstruction...I was really clear all the way along you know, saying, well no, actually I wasn’t clear, I said um (pause) I didn’t think I wanted it but I wouldn’t rule it out, and I was doing that in part because I didn’t want to be seen as being (pause) completely rigid. I think I was clear in my own mind that I didn’t want it ....I didn’t realise the implications of saying that, because what he did was he left a flap of skin that apparently is quite common...and that is why I have had recent surgery to get rid of that”

(Cath, cancer services user).



# Seeing oneself reflected in cancer narratives



- “Books about cancer tell stories. Those who write them offer recognisable narratives of diagnosis, of treatment and or prognosis. Those who read them often do so in search of the comforting hope of survival. Faced with a sudden change in the story of their lives following a cancer diagnosis, many rehearse the possible trajectories which now present themselves through the accounts of those who have been there before them” (Stacey, 1997, p 1).

Being a lesbian it's about everything you do, it's about the way you carry yourself, the way you dress, the things that you're interested in, your culture, your lifestyle, who your friends are, how you relate to the straight world, how you view the media, what books you read, all that sort of stuff. And all of that doesn't stop just because you've got cancer and, you know, just the experience of being on the internet looking for cancer stuff but thinking, I wonder if there's any specific lesbian breast cancer stuff? Oh no, silly me for looking. And I think in a way, that lack of information reinforces sort of negative stereotype. If you were feeling bad about yourself, you've got low self esteem or, you know, had the experience in homophobic abuse, and then you went somewhere and you couldn't find the information you wanted, it kind of reinforces the difference

# Epistemologies of LB women's lived experiences of breast cancer



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# Dissemination - influencing policymakers



Service users were invited as cancer ambassadors at a 10 Downing Street reception held by Sarah Brown and Andy Burnham.  
23 March 2010



# Promoting QOL for LGBT people with cancer



## Breast Cancer Care

- Macmillan — seminar for cancer professionals
- Practice guidance

<http://www.esrc.ac.uk/my-esrc/grants/RES-192-22-0111/read>



**WE ARE  
MACMILLAN.  
CANCER SUPPORT**



**Knowledge exchange  
programme  
RES-192-22-0111**

# Challenges of involvement



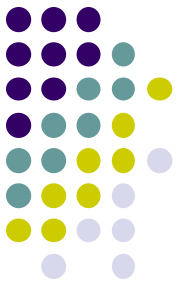
- Grounded in service user lived experience
- Lends authority with stakeholders
- Users with life threatening conditions
- Continuity and change
- Lengthy process
- Small amount of funding which did not recognise time factors
- Meetings in London
- Evaluate the difference that SU involvement makes

# The cancer journey for LGBT people



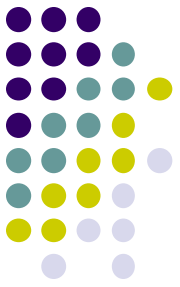
- Prevention
- Screening
- Diagnosis
- Treatment and care
- Survivorship





What would cancer equality look like for LGBT people?

# What would cancer equality look like for LGBT people?



- Services would routinely consider LGBT people as a population of concern.
- Equality and diversity policy statements would specifically include LGBT people.
- Language used to describe LGBT people would not pathologise them.
- Data collection would routinely include sexual orientation and gender identity.
- Inclusion of LGBT people within health inequalities initiatives.

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# Distinctive experiences of cancer care

Doctors never talked  
in front of patient as if  
they were not there

*Always treated with  
respect and dignity  
by hospital staff*

**Never felt treated  
as a set of cancer  
symptoms rather  
than as a whole  
person**

*Hospital staff  
always did  
everything they  
could to control  
their pain*

Patient was given information  
about support / self help groups  
for people with cancer

Differences on 16 domains  
where LGB people  
reported less favourable  
treatment